Agency for Healthcare Research and Quality
Advancing Excellence in Health Care

NATIONAL QUALITY MEASURES CLEARINGHOUSE

# General

## Title

Sickle cell disease (SCD): percentage of children in a state ages 2 through 15 years old with sickle SCD who received transcranial Doppler (TCD) ultrasonography during the measurement year.

## Source(s)

Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC). Basic measure information: transcranial Doppler ultrasonography screening for children with sickle cell disease. Ann Arbor (MI): Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC); 2014 Jan 28. 40 p. [20 references]

# Measure Domain

## Primary Measure Domain

Population Health Quality Measures: Population Process

## Secondary Measure Domain

Does not apply to this measure

# Brief Abstract

## Description

This measure is used to assess the percentage of children in a state ages 2 through 15 years old (ages 24 months and older but less than 16 years) with sickle cell disease (SCD) who received transcranial Doppler (TCD) ultrasonography during the measurement year.

## Rationale

Approximately 2,000 infants are born with sickle cell disease (SCD) in the United States each year, a condition that occurs predominantly in people of African and Hispanic descent. Among children with SCD, approximately 11% experience a stroke by 20 years of age. Transcranial Doppler (TCD) is used to assess the risk of stroke by detecting abnormally high blood flow velocities in the brain. When these abnormal TCD results are followed by blood transfusion treatment, the risk of first stroke is reduced by 92%. However, despite the usefulness of TCD screening to guide stroke prevention, studies report that only

45% to 68% of children with SCD receive annual TCD screening.

Clinical guidelines and the results of randomized controlled trials indicate that providers should perform TCD annually to identify those children with SCD who are at high risk for stroke. There are no existing quality measures for the use of TCD in children with SCD.

## Evidence for Rationale

Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC). Basic measure information: transcranial Doppler ultrasonography screening for children with sickle cell disease. Ann Arbor (MI): Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC); 2014 Jan 28. 40 p. [20 references]

## Primary Health Components

Sickle cell disease (SCD); screening; Transcranial Doppler (TCD) ultrasonography; children

## Denominator Description

The eligible population for the denominator is the number of children in a state ages 2 through 15 years old (greater than or equal to 24 months but less than 16 years) with sickle cell disease (SCD) during the measurement year (January 1 to December 31) (see the related "Denominator Inclusions/Exclusions" field).

## Numerator Description

The eligible population for the numerator is the number of children in a state ages 2 through 15 years old (ages 24 months and older but less than 16 years) with sickle cell disease (SCD) who received transcranial Doppler (TCD) ultrasonography during the measurement year (January 1 to December 31) (see the related "Numerator Inclusions/Exclusions" field).

# Evidence Supporting the Measure

## Type of Evidence Supporting the Criterion of Quality for the Measure

A clinical practice guideline or other peer-reviewed synthesis of the clinical research evidence

A formal consensus procedure, involving experts in relevant clinical, methodological, public health and organizational sciences

A systematic review of the clinical research literature (e.g., Cochrane Review)

One or more research studies published in a National Library of Medicine (NLM) indexed, peer-reviewed journal

## Additional Information Supporting Need for the Measure

*Sickle Cell Disease Prevalence and Incidence*
Sickle cell disease (SCD) is one of the most common genetic disorders in the United States (Kavanagh et al., 2011). The National Heart, Lung and Blood Institute (NHLBI) (2002) estimates that 2,000 infants are born with SCD in the United States (U.S.) each year. SCD affects 70,000 to 100,000 children and adults in

the United States, predominantly those of African and Hispanic descent (Hassell, 2010).

*Sickle Cell Disease Pathology and Severity*
Vaso-occlusion (the sudden blockage of a blood vessel caused by the sickle shape of abnormal blood cells) is responsible for most complications of SCD, including pain episodes, sepsis, stroke, acute chest syndrome, priapism, leg ulcers, osteonecrosis and renal insufficiency (Steinberg, 1999). In addition, SCD can have hemolytic and infectious complications that result in morbidity and mortality in children with SCD (Kavanagh et al., 2011).

*Sickle Cell Disease Burden in Daily Life*
The effect of SCD on children and families is significant: severe pain episodes and hospitalizations restrict daily activities and reflect negatively on school attendance and performance, sleep, and social activities (Lemanek, Ranalli, & Lukens, 2009; Alvim et al., 2005). Although medical management of SCD continues to improve over time, 196 U.S. children died from SCD-related causes between 1999 and 2002 (Yanni et al., 2009).

*Sickle Cell Disease Cost*
In a study of health care utilization among low income children with SCD between 2004 and 2007, 27% of these children required inpatient hospitalization and 39% used emergency care during a year. Of these children, 63% averaged one well-child visit per year and 10% had at least one outpatient visit with a specialist (Raphael et al., 2009). Patients with SCD use many parts of the health care system, incurring significant costs. In 2009, mean hospital charges for children with SCD and a hospital stay were $23,000 for children with private insurance and $18,200 for children enrolled in Medicaid (HCUPnet, Healthcare Cost and Utilization Project, 2012). Kauf et al. (2009) estimate the lifetime cost of health care per patient with SCD to be approximately $460,000.

*Performance Gap – Transcranial Doppler (TCD) Screening*
Despite the value of TCD screening as a means of stroke prevention, a 2008 study at the Texas Children's Sickle Cell Center reported that only 45% of children with SCD received annual TCD screenings and that patients with private insurance were three times more likely to complete more than 50% of ordered TCD screenings than patients with Medicaid (Raphael et al., 2008). In a retrospective cohort study of children aged 2 to 16 years old with SCD enrolled in Tennessee Medicaid, Eckrich et al. found that rates of TCD screening increased over time, with 2.5% receiving TCD screening in 1997 and 68.3% receiving screening in 2008. However, 31% of study participants received no TCD screening during the entire 11-year study period (1997-2008) (Eckrich et al., 2013). Interviews with 36 caregivers of children with SCD revealed that 22% of caregivers had no knowledge of TCD screening, and 42% were unaware that TCD screening should be performed yearly (Bollinger et al., 2011).

## Evidence for Additional Information Supporting Need for the Measure


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Eckrich MJ, Wang WC, Yang E, Arbogast PG, Morrow A, Dudley JA, Ray WA, Cooper WO. Adherence to transcranial Doppler screening guidelines among children with sickle cell disease. Pediatr Blood Cancer. 2013 Feb;60(2):270-4. PubMed

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Lemanek KL, Ranalli M, Lukens C. A randomized controlled trial of massage therapy in children with sickle cell disease. J Pediatr Psychol. 2009 Nov-Dec;34(10):1091-6.

National Heart, Lung and Blood Institute (NHLBI). The management of sickle cell disease. 4th ed. Bethesda (MD): National Institutes of Health, National Heart, Lung and Blood Institute, Division of Blood Diseases and Resources; 2002 Jun. 188 p.

Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC). Basic measure information: transcranial Doppler ultrasonography screening for children with sickle cell disease. Ann Arbor (MI): Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC); 2014 Jan 28. 40 p. [20 references]

Raphael JL, Dietrich CL, Whitmire D, Mahoney DH, Mueller BU, Giardino AP. Healthcare utilization and expenditures for low income children with sickle cell disease. Pediatr Blood Cancer. 2009 Feb;52(2):263-7. PubMed

Raphael JL, Shetty PB, Liu H, Mahoney DH, Mueller BU. A critical assessment of transcranial doppler screening rates in a large pediatric sickle cell center: opportunities to improve healthcare quality. Pediatr Blood Cancer. 2008 Nov;51(5):647-51. PubMed

Steinberg MH. Management of sickle cell disease. N Engl J Med. 1999 Apr 1;340(13):1021-30. PubMed

Yanni E, Grosse SD, Yang Q, Olney RS. Trends in pediatric sickle cell disease-related mortality in the United States, 1983-2002. J Pediatr. 2009 Apr;154(4):541-5. PubMed

## Extent of Measure Testing

Reliability

*Data*. Our testing data consisted of claims from six states with a moderateâ€toâ€high prevalence of sickle cell disease (SCD): Florida, Illinois, Louisiana, Michigan, South Carolina, and Texas. Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC) tested this measure using claims drawn from 5 consecutive years of Medicaid Analytic eXtract (MAX) administrative claims data provided by the Centers for Medicare & Medicaid Services (CMS). The measure was implemented using MAX data from each state to evaluate the consistency of results for the most current 5-year period for which the MAX data were available. This measure was tested as specified, which requires assessment among the entire population of children with SCD ages of 2 through 15 years old (that is, 24 months and older but less than 16 years) within the measurement year. This measure does not involve sampling; all SCD cases meeting the inclusion criteria are included in the measure specification.

For two states (Michigan and Illinois), additional administrative claims data were obtained directly from the respective state Medicaid programs. Ultimately, these data originate from the same source as the MAX data; Q-METRIC tested this measure using these independently acquired data to evaluate the

reliability of Transcranial Doppler (TCD) screening measure results obtained using MAX administrative claims data. In addition, we conducted a medical record review in Michigan to evaluate the coding reliability and accuracy of administrative claims for TCD screening.

Refer to the original measure documentation for additional testing data.

Validity
*Face Validity*. Face validity is the degree to which the measure construct characterizes the concept being assessed. The face validity of this measure was established by a national panel of experts and advocates for families of children with SCD convened by Q-METRIC. The Q-METRIC expert panel included nationally recognized experts in SCD, representing hematology, pediatrics, and SCD family advocacy. In addition, measure validity was considered by experts in state Medicaid program operations, health plan quality measurement, health informatics, and health care quality measurement. In total, the Q-METRIC SCD panel included 14 experts, providing a comprehensive perspective on SCD management and the measurement of quality metrics for states and health plans.

The Q-METRIC expert panel concluded that this measure has a very high degree of face validity through a detailed review of concepts and metrics considered to be essential to effective SCD management and treatment. Concepts and draft measures were rated by this group for their relative importance. This measure was among the most highly rated, receiving an average score of 8.5 (with 9 as the highest possible score).

*Validity of Coded Data*. This measure is based on administrative claims data; therefore, the validity of the coded data reported in Medicaid claims was assessed through a medical record review. As noted in the Reliability section, a subset of SCD cases was identified from Michigan Medicaid claims data, and a chart audit was conducted to compare administrative claims data with the corresponding medical records at Children's Hospital of Michigan, Hurley Medical Center, and the University of Michigan Health System.

## Evidence for Extent of Measure Testing

Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC). Basic measure information: transcranial Doppler ultrasonography screening for children with sickle cell disease. Ann Arbor (MI): Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC); 2014 Jan 28. 40 p. [20 references]

# State of Use of the Measure

## State of Use

Current routine use

## Current Use

not defined yet

# Application of the Measure in its Current Use

## Measurement Setting

Ambulatory/Office-based Care

Community Health Care

Hospital Inpatient

Hospital Outpatient

Regional, County, or City Public Health Programs

State/Provincial Public Health Programs

### Type of Care Coordination

Coordination between providers and community

Coordination between providers and patient/caregiver

### Professionals Involved in Delivery of Health Services

not defined yet

### Least Aggregated Level of Services Delivery Addressed

State/Provincial

### Statement of Acceptable Minimum Sample Size

Does not apply to this measure

### Target Population Age

Age 2 to 15 years

### Target Population Gender

Either male or female

## National Framework for Public Health Quality

### Public Health Aims for Quality

Population-centered

## National Strategy for Quality Improvement in Health Care

### National Quality Strategy Aim

Healthy People/Healthy Communities

## National Quality Strategy Priority

Effective Communication and Care Coordination
Prevention and Treatment of Leading Causes of Mortality

# Institute of Medicine (IOM) National Health Care Quality Report Categories

## IOM Care Need

Living with Illness

## IOM Domain

Effectiveness

# Data Collection for the Measure

## Case Finding Period

The measurement year (January 1 to December 31)

## Denominator Sampling Frame

Geographically defined

## Denominator (Index) Event or Characteristic

Clinical Condition

Encounter

Patient/Individual (Consumer) Characteristic

## Denominator Time Window

not defined yet

## Denominator Inclusions/Exclusions

Inclusions
The eligible population for the denominator is the number of children in a state ages 2 through 15 years old (greater than or equal to 24 months but less than 16 years) with sickle cell disease (SCD) during the measurement year (January 1 to December 31).

Note:

Eligible children are restricted to those identified with sickle cell anemia based on appropriate International Classification of Diseases, Ninth Revision (ICD-9) codes on three or more separate health care encounters (refer to Table 1 of original measure documentation) during the measurement year.

Children must be continuously enrolled in Medicaid during the measurement year.
*Intake Period*: January 1 of the measurement year through December 31 of the measurement year.

Exclusions

Children who have a 2nd or 16th birthday during the measurement year are excluded from the calculation.
Claims in the administrative records for SCD variants other than sickle cell anemia (refer to Table 3 of the original measure documentation) do not count toward the "three or more separate health care encounters" criteria.

## Exclusions/Exceptions

not defined yet

## Numerator Inclusions/Exclusions

Inclusions
The eligible population for the numerator is the number of children in a state ages 2 through 15 years old (ages 24 months and older but less than 16 years) with sickle cell disease (SCD) who received transcranial Doppler (TCD) ultrasonography during the measurement year (January 1 to December 31). TCD is identified as any of five acceptable ultrasonography tests (refer to Table 2 of original measure documentation).

Exclusions
Unspecified

## Numerator Search Strategy

Fixed time period or point in time

## Data Source

Administrative clinical data

## Type of Health State

Does not apply to this measure

## Instruments Used and/or Associated with the Measure

Unspecified

# Computation of the Measure

## Measure Specifies Disaggregation

Does not apply to this measure

## Scoring

Rate/Proportion

## Interpretation of Score

Desired value is a higher score

## Allowance for Patient or Population Factors

not defined yet

## Standard of Comparison

not defined yet

# Identifying Information

## Original Title

Transcranial Doppler ultrasonography screening for children with sickle cell disease.

## Measure Collection Name

Sickle Cell Disease Measures

## Submitter

Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC) - Academic Affiliated Research Institute

## Developer

Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC) - Academic Affiliated Research Institute

## Funding Source(s)

This work was funded by the Agency for Healthcare Research and Quality (AHRQ) and the Centers for Medicare & Medicaid Services (CMS) under the CHIPRA Pediatric Quality Measures Program Centers of Excellence grant number U18 HS020516.

## Composition of the Group that Developed the Measure

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## Financial Disclosures/Other Potential Conflicts of Interest

Unspecified

## Adaptation

This measure was not adapted from another source.

## Date of Most Current Version in NQMC

2014 Jan

## Measure Maintenance

Unspecified

## Date of Next Anticipated Revision

Unspecified

## Measure Status

This is the current release of the measure.

The measure developer reaffirmed the currency of this measure in January 2016.

## Measure Availability

Source available from the Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC) Web site . Support documents are also available.

For more information, contact Q-METRIC at 300 North Ingalls Street, Room 6C08, SPC 5456, Ann Arbor, MI 48109-5456; Phone: 734-232-0657; Fax: 734-764-2599.

## NQMC Status

This NQMC summary was completed by ECRI Institute on July 25, 2014. The information was verified by the measure developer on September 16, 2014.

The information was reaffirmed by the measure developer on January 7, 2016.

## Copyright Statement



# Production

## Source(s)

Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC). Basic measure information: transcranial Doppler ultrasonography screening for children with sickle cell disease. Ann Arbor (MI): Quality Measurement, Evaluation, Testing, Review, and Implementation Consortium (Q-METRIC); 2014 Jan 28. 40 p. [20 references]

# Disclaimer

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